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# **Compassionate Social Security Disability Allowance for Cancer Patients: Providing Access to Financial Security and Necessary Healthcare Coverage**

## **Recommendations To Standardize And Improve Access For Oncology Patients To The Social Security Disability System**

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## Introduction

Patient Advocate Foundation (PAF), a national non-profit organization, provides direct, sustained case management services to patients with an array of chronic, debilitating and/or life-threatening diseases, resolving more than 44,700 individual cases and providing support and education to more than 6.8 million Americans in 2007. The relationships established by PAF's staff with patients is one that fosters trust, confidence and loyalty as its team works collaboratively and cooperatively with patients, their medical providers, their insurers and employers to achieve favorable resolutions that remove obstacles to needed healthcare, while also restoring financial dignity for the patient and their family and addressing job retention issues that impact them both now and in the future.

The experiences of the Patient Advocate Foundation professional case managers, who have served Americans with cancer since April 1996 providing services and information to more than 21 million people in America, reflect the hardship encountered by patients and caregivers attempting to navigate the current Social Security disability system. These difficulties often result in lack of access to healthcare services, loss of all financial stability, and negative survival outcomes for these critically ill patients. A successful application and approval by the Social Security Administration for the cancer patient is the key to being able to continue health insurance coverage; often that health insurance coverage is of greater concern to this population than a monthly check. A positive determination by the Social Security Administration allows the patient to access benefits available to disabled patients, including early entry into Medicare, Medicaid benefits if they meet the income and resource benefits, and the ability to continue private coverage extensions such as COBRA and access to long term disability benefits. PAF collects extensive data, which is housed in a customized database containing 237 unique data fields, on every patient served through the Patient Services division, thus providing us with an in-depth view of the issues facing patients as they seek to access Social Security disability benefits. This report contains charts and graphs derived from the case data of patients served in 2007 that will illustrate PAF's experience with the current Social Security disability process as well as offering a breakdown of the demographics of these patients seeking disability.

The professional case managers of Patient Advocate Foundation represent a broad cross section of healthcare specialties including advanced degree nurses, oncology nurse case managers, Social Security, Medicaid and Medicare specialists, coding and billing experts, pediatric specialists and licensed clinical social workers. It is through their direct experiences with patients nationwide seeking approval for Social Security Disability benefits that we can provide data-driven testimony to the Commissioner and to the members of the Social Security Committee regarding the primary barriers cancer patients face when seeking to access the disability system. We also respectfully submit process recommendations for your consideration that, if implemented, would greatly benefit oncology patients in the future. PAF applauds the efforts of the Social Security Administration as they examine ways to further eliminate barriers to financial resources and healthcare benefits for cancer patients in our country. By implementing a Compassionate Allowance provision for certain cancer patients, based on disease type and/or progression and stage, the most obviously disabled individuals would be granted disability status much more quickly and would also benefit the already overburdened healthcare providers by scaling back the volume of medical support and documentation currently required by the Social Security eligibility determination process.

## **Overview of Global Issues**

PAF has identified seven major areas of concern within the current Social Security Disability process. PAF respectfully submits the following observations for your consideration:

**Global Issue 1: Disability approval is critical for expedient access to many state, federal and/or employer sponsored health benefit programs, such as Medicaid, Medicare, and COBRA extensions.**

**Global Issue 2: Timely coordination of disability and health benefit applications is critical to long term insurability for permanently disabled individuals. In essence, the Social Security Administration is the gatekeeper for all subsequent health benefits and entitlements for cancer patients.**

**Global Issue 3: The lengthy Social Security application process often prevents cancer patients from receiving necessary cost of living assistance during initial period of acute illness and can completely exclude certain patients from ever receiving benefits as they succumb to disease prior to determination**

**Global Issue 4: Lack of education regarding available programs, the actual disability application process and eligibility criteria among providers, patients and in some instances even SSA employees often result in a high percentage of application denials. This results in delayed access to necessary financial assistance and places further burdens on critically ill patients as they attempt to navigate a laborious administrative process.**

**Global Issue 5: The lack of coordination among state and federal agencies resulting in multiple layers of application requirements and documentation submissions, preventing potentially qualified beneficiaries from fully accessing entitlements.**

**Global Issue 6: The oncology community tends to view patient outcomes in short term increments, measuring success in months not years. Oncology treatment protocols are most frequently delivered in cycles that vary in length and include different modalities such as chemotherapy, radiation, and/or**

**surgical intervention that result in debilitating side effects and lengthy recovery periods. The current disability language requires patients to be unable to work for a period of 12 consecutive months; this creates a disconnect between the oncology and the Social Security communities.**

**Global Issue 7: For patients receiving Medicaid as a result of a favorable Social Security Disability determination, the actual receipt of monthly SSDI payments beginning after the five-month waiting period may result in their income level now exceeding the Medicaid income guidelines, thus resulting in the revocation of their Medicaid benefits, rendering them uninsured and compromising their continued access to oncology care.**

## Global Recommendation One

### **Cancer patients diagnosed with stage III or IV disease should receive automatic presumptive disability.**

- The current definition of presumptive disability is cited as, “If the evidence available at the time we make the finding reflects a high degree of probability that you are disabled or blind.”<sup>1</sup>
- Patients who are diagnosed with recurrent disease or in the later stages of cancer often have survival rates of less than six months. According to the American Cancer Society’s publication, “*Cancer Facts & Figures 2008*,” the one-year relative survival for lung cancer has slightly increased to 41%. The survival rate for lung cancer patients diagnosed with localized disease is usually 49%, however, only 16% of lung cancer patients are diagnosed in early stages allowing for localized diagnosis. One-year patient survivability when diagnosed with non-localized pancreatic cancer is only 5%, but for all stages there is a one-year survival rate of 24%. Liver cancer patients have a 14% survival rate in the first year of disease. This random sampling of cancer survivorship figures demonstrates the need for inclusion of certain types and stages of cancer in the compassionate allowance provision.
- Many patients who are too ill to continue working are required to utilize COBRA benefits, if available, to ensure their continued ability to access treatment. Unfortunately, current law only requires COBRA coverage for 18 months, potentially leaving a patient uninsured for a period of 11 months prior to Medicare eligibility. There are currently stringent guidelines in place relating to the application process for a COBRA extension. In order for a patient to qualify for the additional 11 month disability extension which is designed to transition qualified disabled patients from COBRA into Medicare coverage (29 months) there are very specific time parameters that must be met. First, the patient must have a determination letter from Social Security Administration that includes a statement that the date they were “deemed disabled” occurred within the first 60 days of COBRA coverage. Second, this letter must be submitted to the COBRA administrator within 60 days of receipt from Social

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<sup>1</sup> [http://www.socialsecurity.gov/OP\\_Home/cfr20/416/416-0933.htm](http://www.socialsecurity.gov/OP_Home/cfr20/416/416-0933.htm)

Security Administration prior to the expiration of COBRA coverage.<sup>2</sup> *The issue that is experienced by our patients as a result of current determination delays is two-fold: they are unable to afford COBRA initially as a result of no income to pay for the premium and/or they do not receive the Social Security determination within the strict timeframe as outlined above.* According to the COBRA statute, employees are responsible for the monthly health insurance premium, up to 102% which is inclusive of 100% of the premium combined with a 2% administration fee. PAF case managers work diligently to counsel and educate patients on COBRA extension requirements and the necessity of maintaining continuous healthcare coverage without lapses which can greatly impact their continuity of care and future insurability.

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<sup>2</sup> [www.dol.gov/ebsa/faqs/faq\\_consumer\\_cobra.html](http://www.dol.gov/ebsa/faqs/faq_consumer_cobra.html)

## **Global Recommendation Two**

### **Reform the Disability Application process to prevent delays in rendering a favorable determination.**

- Significant reform within the disability application process will prevent delays in rendering a permanent disability decision, and will allow timely access to care. PAF case managers will request that a presumptive decision be made until the formal process can be completed when it becomes clear that a delay in SSA rendering a permanent disability decision would prevent a patient from being able to access medical programs, thus impeding a patient's ability to receive treatment.
- The requirement that medical records from all treating facilities and/or providers be supplied for review significantly slows the process for disability approval. Oncology patients are treated with multiple modalities (including chemotherapy, radiation therapy and/or surgery). PAF proposes the development of an electronic submission portal option which would include a physician verification form, allowing an expedient verification of both the diagnosis and staging information. The verification form should include site of pathology, date, pathology report, the documenting physician and their UPIN number. The questions currently asked on the application form do not apply to patients with terminal diseases. Questions should be limited to specific information needed for the determination and keep the length of the form to one page or less. Multi-page application forms deter physician participation and contribute to delay in processing the determination.
- PAF strongly endorses the use of electronic medical records as a mechanism for more expedient sharing of comprehensive medical information. Currently, there may be fees associated with the provision of hard copy medical records that are usually passed on to the patient. Electronic medical records would eliminate the cost and waiting currently associated with obtaining medical records. Eliminating the time required to collect all of the medical records would allow disability determination to be accomplished without delay.
- The current SSDI application for benefits and Adult Disability Report forms are thorough and entirely appropriate for many applicants. PAF understands the need to separate disability information and financial information as determinations are made by different teams in

different locations. For cancer patients, however, these forms request information and verifications not necessary for a diagnosis-based determination of disability. The SSDI application and Adult Disability application can be streamlined into a single, three page double-sided form incorporating the financial information needed to determine the amount of SSDI/SSI payments as well as the diagnosis, stage, and physician contact information for disability and compassionate allowances program inclusion. (See attached recommended form.)

- FAST track the application to disability determination services (DDS). The FAST Track system is in place but disability case workers are often not aware of the process. Currently, disability supervisor assistance must be obtained to access this system.
- Create an abbreviated application which would combine with a process to provide direct application support through the utilization of SSA case managers.
- Availability of the application needs to meet the needs of all applicants. An online application could be available to patients enabling those who are able to complete the process themselves electronically or by working directly with the SSA case manager or advocate. Applications also need to be available via mail for applicants with no access to an online process.
- Patients should be provided comprehensive contact information for the case worker handling their application including direct phone number and e-mail address. This contact information should also be reflected on all correspondence received by the patient.

## **Global Recommendation Three**

### **Simplification of the disability application process would improve compliance.**

- When an appointment for a disability application/interview is scheduled, a letter specifying the information that must be provided in order for a favorable determination to be rendered should be mailed to the patient prior to the appointment. This would expedite the time needed to complete the application and submit for disability determination.
- Review of the language in place in the current determination letters received by patients should be considered for revision as they are often a source of confusion. Most patients are not aware they have applied for both SSI and SSDI at the time of initial application. If a patient receives a letter from SSI denying benefits because they exceed limits for household income or assets, they assume the entire application is denied. They do not understand that the SSDI application is still pending review and do not follow up with submitting additional information. Additionally, patients who receive denials based on work credits often have a lack of understanding of what this means and file appeals requiring review and reconsideration.

## **Global Recommendation Four**

**Education is the key for successful implementation of the compassionate allowance process.**

- Comprehensive educational programs need to be available for internal and external stakeholders regarding the Social Security Disability application and compassionate allowance processes. Education targeted to providers, case workers, and social workers needs to focus on the critical aspects of disability application submissions, including 1) required supporting documentation that must be submitted to process the claim; 2) subsequent benefit entitlements for patients found to meet disability guidelines.
- Provide educational and advancement opportunities for SSA disability counselors to become specialized to work with critically ill patients and more knowledgeable regarding the presumptive disability process.

## Global Recommendation Five

### Extend immediate Medicare coverage to patients with a stage III or IV cancer diagnosis.

- Cancer patients with compassionate allowance determinations also should be extended the ability to obtain Medicare/Medicaid coverage at the time of compassionate disability approval. The precedent for an exception already exists with Amyotrophic Lateral Sclerosis (ALS) also known as Lou Gehrig's disease as well as End-Stage Renal Disease (ESRD). People with ALS are automatically eligible for Parts A and B the month their disability benefits begin. Patients with ESRD who are receiving dialysis treatment are eligible for Medicare on the first day of the fourth month of dialysis treatments.<sup>3</sup> According to the SSA publication: *2008 Medicare & You Handbook*:

- "People with ALS (Amyotrophic Lateral Sclerosis, or Lou Gehrig's disease) automatically get Part A the month their disability benefits begin."<sup>4</sup>
- "People with ALS (Amyotrophic Lateral Sclerosis, or Lou Gehrig's disease) automatically get Part B the month their disability benefits begin."<sup>5</sup>
- "Medicare is health insurance for people age 65 or older, under age 65 with certain disabilities, and any age with End-Stage Renal Disease (permanent kidney failure requiring dialysis or a kidney transplant)."<sup>6</sup>
- The Social Security website shows a listing of impairments on their "Disability Evaluation Under Social Security".<sup>7</sup>
- ALS is in the listing of neurological disorders<sup>8</sup>

For ESRD, the website states: "*Chronic hemodialysis or peritoneal dialysis* A report from an acceptable medical source describing the chronic renal disease and the need for ongoing dialysis is sufficient to satisfy the requirements in 6.02A."

- When a patient is deemed disabled, a "flagging system" should be triggered to direct the social services worker to complete both SSI and the Medicaid applications. The SSI

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<sup>3</sup> Medicare Coverage of Kidney Dialysis and Kidney Transplant Services

<sup>4</sup> *2008 Medicare & You Handbook*, Page 12 paragraph 2

<sup>5</sup> *2008 Medicare & You Handbook*, Page 15 paragraph 2

<sup>6</sup> *2008 Medicare & You Handbook*, Page 6 paragraph 1

<sup>7</sup> Blue Book - 2006

<sup>8</sup> *2008 Medicare & You Handbook*, 11.10

Medicaid application currently has 10 questions with regard to income. However, this is not routinely completed for patients. Currently, there are states that have initiated a process that combines the SSI and Medicaid applications into a single application.

- What is Medicaid? Medicaid is a jointly funded, Federal-State health insurance program for low-income and needy people. It covers children, the aged, blind, and/or disabled and other people who are eligible to receive federally assisted income maintenance payments.
  - Thirty-two states and the District of Columbia provide Medicaid eligibility to people eligible for Supplemental Security Income (SSI) benefits. In these States, the SSI application is also the Medicaid application. Medicaid eligibility starts the same months as SSI eligibility.
  - The following jurisdictions use the same rules to decide eligibility for Medicaid as SSA uses for SSI, but require the filing of a separate application: Alaska, Idaho, Kansas, Nebraska, Nevada, Oregon, Utah, Northern Mariana Islands.
  - The following States use their own eligibility rules for Medicaid, which are different from SSA's SSI rules. In these states a separate application for Medicaid must be filed: Connecticut, Hawaii, Illinois, Indiana, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, Virginia<sup>9</sup>
- As previously stated, if a patient is deemed disabled and is eligible for SSI (which provides them access to immediate Medicaid), this allows the patient to begin treatment. When SSDI benefits begin after the five month waiting period, the patient often is found to exceed Medicaid income guidelines, and they lose eligibility rendering them uninsured in the middle of treatment. Allowing for full coverage Medicaid buy-in or to have premium assistance if the patient has access to private health insurance would allow the patient to continue treatment.
- Self-employed individuals often find that they are not entitled to any disability benefits because their work credits are not within the 10-year look back. The 10-year look back period should be eliminated allowing for patients that have in fact contributed into the social security system at any point, to be entitled for disability consideration.

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<sup>9</sup> <http://www.socialsecurity.gov/disabilityresearch/wi/medicaid.htm>

## **Global Recommendation Six**

**Shorten the length of time advanced cancer patients must be unable to work prior to meeting disability requirements.**

- Provide a secure physician portal for providers to submit required and/or requested information for their patients while removing the six-month life expectancy as a requirement to qualify for presumptive disability. These changes would encourage physicians to assist their patients who are applying for disability.
- Shorten the application process to empower disability applicants with the ability to complete the application.

## **Global Recommendation Seven**

**Allow a Medicaid/Medicare buy-in program for those patients who would otherwise lose insurance coverage based on current income guidelines.**

- Timely coordination of benefit applications is critical to long term insurability of permanently disabled individuals. The current system allows the patient to be deemed disabled immediately through the TERI process defined by SSA as “A critical case involving terminal illness” but this does not expedite initiation of benefits.<sup>10</sup> Once deemed disabled and if the income requirements for SSI are met, SSI benefits may be received that entitle the patient to Medicaid. These benefits terminate when SSDI begins because the income guidelines are then exceeded.
- The five-month waiting period for SSDI benefits is a major problem for patients undergoing cancer treatment and experiencing resulting debt crisis. This provision should be changed to state that if the patient is eligible for SSI, at any time during this five-month period of time prior to your entitlement to SSDI benefits, the patient will qualify for Medicaid coverage. Upon entitlement to SSDI a “grandfather clause” would be applied so that Medicaid eligibility would continue until such time as treatment is completed or the patient becomes eligible for Medicare. Patients who have worked and possess the required work credits often find themselves in an unenviable quandary as typically, due to their work and income history, they have resources in excess of the Medicaid limits and are excluded from any eligibility for Medicaid.
- The purchase of Medicare supplement insurance by SSDI Medicare recipients is not universally available at this time. PAF recommends approval of Medicare supplement policies that would pay for Medicare deductibles as an alternative to state funded Medicaid programs.

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<sup>10</sup> [www.socialsecurity.gov/OP\\_Home/hallex/I-04/I-4-3-43.html](http://www.socialsecurity.gov/OP_Home/hallex/I-04/I-4-3-43.html)